

A STUDY AMONG PARENTS OF CHILDREN WITH MENTAL RETARDATION

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ABSTRACT

The parents of children with female mentally challenged absolutely face more difficulties than parents of children with male mentally challenged, which in turn affect their quality of life. Many factors can influence the quality of life of the parents with mentally challenged children in family. Parents are in family who deal with the issues associated with child's disability and also maintain the household so it is very important for parents to take some time to care for themselves as individuals and getting enough sleep, eating regular meals, taking a short walk, and doing the things that they really enjoy. Parents having a child with mentally challenged experience a variety of stressors and stress reactions related to the child's disability and known to get impacted in many ways because of having a special child. The present study aims to find out the "A Study among Parents of Children with Mental Retardation" studying in special schools of Dharmapuri District of Tamilnadu.

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INTRODUCTION

Mental retardation is one of the most widely recognized and most easily misunderstood areas of special education. It is widely recognized in that most people think of a visible form of retardation such as Down syndrome. However, those with Down syndrome are not the only ones affected by this handicapping condition. It is often misunderstood, due in part to changing definitions and trends in educating these students. Understanding the definitions, trends, and programs related to mental retardation may help to clarify who these young people are and the approaches taken to help them develop to their fullest potential.

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1.1 Definition of Mental Retardation

There are various definitions of mental retardation. Some defines it basing on the intelligence test scores; some defines it basing on the failure of the social performance, some basing on the cause or essential nature of retardation such as brain damage. But of all these the most widely accepted definition of mental retardation today is that adopted by the American Association of Mental Deficiency (AAMD) which states that – Mental Retardation refers to significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period (Grossman, 1973). In other words the mentally retarded person is one who has suffered an impairment of his ability to think, learn and reason.

1.1.2 Classification of American Association of Mental Retardation prior to 1973

Degrees of Retardation	I.Q Range
Profound	0 – 24
Severe	25 – 39
Moderate	40 – 54
Mild	55 – 69
Borderline	70 – 84

According to American Association of Mental Retardation classified based by their concept of Mental Retardation. Mental retardation divided into five stages.

1.1.3 Differences between the Mental Retardation and Mental Illness

Mental Retardation (has manifestations)	Mental Illness (has symptoms)
Commonly caused by an irreversible genetic anomaly, in utero malfunction, or injury	May be genetic and/or environmental in origin
Cannot be “controlled” or ameliorated via drugs	Can be “controlled” or ameliorated via drugs
Cannot be improved with psychotherapy treatment. (Manifestations can sometimes be somewhat ameliorated via educational interventions and techniques)	Can be improved with psychotherapy treatment
Using modern medicine and treatment, cannot be “cured”	Using modern medicine and treatment, can often be rehabilitated

1.1.4 Signs of Mental Retardation

There are many signs of mental retardation. For example, children with mental retardation may:

1. Sit up, crawl, or walk later than other children;
2. Learn to talk later, or have trouble speaking,

3. Find it hard to remember things,
4. Not understand how to pay for things,
5. Have trouble understanding social rules,
6. Have trouble seeing the consequences of their actions,
7. Have trouble solving problems and/or Have trouble thinking logically.

1.1.5 Characteristics of Mental Retardation

Mental Retardation is a disability characterized by significant limitations both in intellectual functioning and in Adaptive behavior as expressed in conceptual social and practical adaptive skills. This disability originates before the age of 18 (AAMR 2002)

1. Delay in development & Slow reaction
2. Absence of clarity & Inability to learn fast
3. Inability to understand quickly & Inability to decide
4. Inability to remember & Lack of concentration
5. Lack of motor coordination & Age inappropriate behavior

1.1.6 Causes of Mental Retardation: Biological Risk Factors

Biological risk factors are those that develop within the body as part of one's basic biology and organic make up. They include genetic and other inborn features (characteristics) metabolic aspects and interaction of varied complex system of the body. Many biological risk factors are genetic.

1.1.7 Professional Mishandling of Parents: Ignorance

In spite of great technological advances with respect to mental retardation during recent years, a surprising number of professionals in the medical and behavioral sciences have little knowledge about the condition. Misdiagnosis and dispensation of misinformation are still common. Some parents are still assured that their child will "outgrow" the difficulty, and others are confronted with the "hopelessness" of their child's condition and are urged to proceed with immediate institutionalization.

1.1.8 Hopelessness

Those who apply a medical model to mental retardation tend to view it as an "incurable disease" and hence as "hopeless." This orientation generates self-fulfilling and self-limiting prophecies that impede the development of retarded individuals. Furthermore, parents readily detect such defeatist attitudes and either develop similar expectations or resent those who adopt such a negative approach toward their child.

1.1.9 Veil of Secrecy

Some professionals are still reluctant to share information with their clients, allegedly because the information would be too threatening, too uncomfortable, or in some other way would be destructive to the client. This "veil of secrecy" may conceal the more fundamental reason that some professionals minimize their own feelings of insecurity by maintaining a monopoly on information of potential value to their clients.

1.1.10 Parents as Patients

In view of the negative assumptions held by many professionals regarding parents' emotional maladjustment, it is not surprising that they tend to perceive parents as prime candidates for counseling or psychotherapy. Hence parents may be thwarted in obtaining desperately needed information regarding their child's condition and the availability of services to meet his needs. Instead they are likely to find that professionals are eager to unravel their intra psychic conflicts and to explore their marital problems and other areas of "mal-adjustment".

1.1.11 Depression

As already noted, chronic sorrow can be anticipated as a non - pathological reaction to having a retarded child. Typically, parents are disappointed in their child and realistically concerned about his future. To some, mental retardation symbolizes the death of the child and hence precipitates the type of grief reaction associated with the loss of a loved one.

1.1.12 Self-Sacrifice

Some parents dedicate themselves entirely to the retarded child, make great personal sacrifices, and adopt a "martyr" approach to life. Family disruption, including neglect of other children and marital conflicts, may accompany this pattern.

1.1.13 Defensiveness

Parents may become hypersensitive to perceived criticism of their retarded child and respond with resentment and belligerence. In extreme cases they may deny the existence of retardation, rationalize the child's shortcomings, and seek professional opinions to substantiate their own conviction that "there is really nothing wrong" with him.

1.1.14 Aloneness

Man's deep-rooted need for intimacy is never completely fulfilled. There is no way to transcend individual boundaries and to share feelings and perceptions fully with another. Often the last desperate hope of overcoming aloneness is through our children products of our bodies, shaped into our image, literally extensions of ourselves. A retarded child may thwart this hope, because of his limited capacity to communicate and achieve intimacy. Hence, parental feelings of aloneness are likely to be intensified, and parents may feel that they have lost the final chance to achieve intimacy.

1.1.15 Vulnerability

Early fantasies of omnipotence are soon shattered as the young child is repeatedly confronted with his dependence on others and his helplessness to cope with the world. As he matures, he learns that others, too, are not omnipotent, including his parents, teachers, and heroes. Pain, injury, illness, and failure all attest force – fully to personal vulnerability, the tenuousness of one's control over the world, and, indeed, the fragile nature of life itself.

1.1.16 Inequity

From earliest childhood we are conditioned to believe that fairness and justice ultimately prevail. Most members of our society have adopted an orientation to life based on the premise that "good" will triumph and that, in the unlikely event that our judicial system falters, some greater force will ensure that heroes are rewarded and villains punished. When faced with retardation in his child, the parent is overwhelmed by the enormity of the apparent inequity; and his natural reaction is to ask, "Why me?" In his desperate search for an answer to this question, he is likely to entertain two possibilities: either he deserves the "punishment," because of grievous "sins," or the world is neither fair nor just. The former alternative generates guilt, remorse, and self-recrimination; the latter endangers fundamental ethical, moral, and religious beliefs.

1.1.17 Preventing and Aware of Mental Retardation

The health of a baby can depend on how healthy a mother is before pregnancy. Ideally, she should obtain a general health assessment six months before pregnancy that includes:

1. Updating immunizations & reviewing use of medications;
2. Reviewing diet and vitamin supplementation, including folic acid;
3. Considering genetic counseling; and stopping use of alcohol, cigarettes or other tobacco forms, illegal drugs, and legal drugs not approved by the doctor.
4. Getting plenty of rest and sleep & eating nutritious meals;
5. Avoiding alcohol, cigarettes and drugs & avoiding people who are sick;
6. Wearing seat belts in a car; and not lifting heavy objects.

1.1.18 Preventing Method for Intellectual Disabilities during Childhood

Intellectual disability can be prevented during childhood by knowing the causes and taking steps to keep children safe and healthy. These steps include:

1. Childhood immunizations to protect children from at least six diseases that can lead to brain damage. These include measles, mumps, pertussis (whooping cough), Hib disease, varicella (chicken pox), and pneumococcal disease.
2. Injury prevention to avoid brain damage, such as using bicycle helmets and safety seats and seat belts in automobiles; preventing near-drowning; preventing falls and protecting babies from severe shaking.
3. Newborn screening to identify treatable genetic conditions.
4. Reducing the incidence of Reye's syndrome caused by giving medicines containing salicylate (aspirin); instead, using medicines containing acetaminophen (such as Tylenol) to reduce the brain damage caused by Reye's syndrome.
5. Reducing exposure to lead, mercury and other toxins in the environment that are known to cause brain damage.
6. Protecting children from household products that are poisonous. Alexander (1998).

1.2 Objectives

The present study aims to find out the "A Study among Parents of Children with Mental Retardation" studying in special schools of Dharmapuri District of Tamilnadu.

1. To describe the socio-economic status of parents with mental retardation.
2. To determine the level of coping of the mother of children with mental retardation.

3. To study the stress of mothers with respect to selected variables.

METHODOLOGY

The population selected for the study the parents of mentally Retarded children admitted in special schools of Dharmapuri. There are 9 Special Schools in Dharmapuri City. The researcher applied the simple random sampling technique using the lottery method and selected 4 schools for the study. The researcher selected all the students from the above 4 schools which constituted to be a population of 110 respondents using the census method. Descriptive research design was adapted to express the care and support challenges of mentally retarded children. A well-structured interview schedule was used to elicit data.

ANALYSIS AND INTERPRETATIONS

Table – 1: *One way analysis of Variance between Socio Demographic background and Burden Assessment Scale for the Parents of Mentally Retarded Children*

Category	Variables	N	Mean	Std. Deviation	Interference
Age Group	Below 35 years	53	49.38	6.757	F - 0.490 df - 2, 107 Sig. 0.614 p>0.05
	36-45 years	38	50.29	5.690	
	46 years and above	19	48.74	3.588	
Gender	Male	60	49.08	5.938	t - -0.965 Df - 108 Sig. 0.337 p>0.05
	Female	50	50.18	5.934	
Religion	Hindu	82	49.57	5.602	F - 3.501 df - 2, 107 Sig. 0.034 p < 0.05
	Christian	17	51.94	3.992	
	Muslim	11	46.00	8.978	
Education	Illiterate	33	48.30	4.766	F - 0.929 df - 3, 106 Sig. 0.430 p>0.05
	School	45	50.16	5.760	
	Diploma	22	49.55	8.192	
	Under Graduate	10	51.30	4.001	
Occupation	Unemployed	36	48.08	5.347	F - 1.616 df - 3, 106 Sig. 0.190 p>0.05
	Government	14	49.29	3.872	
	Private	31	49.87	6.999	
	Business	29	51.28	5.993	
Type of Family	Nuclear family	81	49.22	6.332	T - -1.063 Df - 108 Sig. 0.290 p>0.05
	Joint family	29	50.59	4.594	
House Status	Own	58	49.52	5.780	T - -0.120 Df - 108 Sig. 0.905 p>0.05
	Rent	52	49.65	6.158	

Locality	Rural	48	48.65	5.681	T - -1.463 Df - 108 Sig. 0.146 p>0.05
	Urban	62	50.31	6.070	
Income	₹1,000 to ₹5,000	46	49.54	6.021	F - 1.479 df - 2, 107 Sig. 0.232 p>0.05
	₹5,001 to ₹10,000	42	48.69	6.182	
	₹10,001 and above	22	51.36	5.057	
Savings	Yes	34	50.56	5.046	T - 1.157 Df - 108 Sig. 0.250 p>0.05
	No	76	49.14	6.273	

3.1 Age Group and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the age group of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the age group of the respondents in the mean score of the parents of mentally retarded children.

Results: F (2,107) – 0.490 p-sig = 0.614. Since p value = sig 0.614 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated F value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the age group of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.2 Gender and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the gender of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the gender of the respondents in the mean score of the parents of mentally retarded children.

Results: T (108) – 0.965 p-sig = 0.337. Since p value = sig 0.337 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated T value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the gender of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.3 Religion and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the religion of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the religion of the respondents in the mean score of the parents of mentally retarded children.

Results: F (2,107) – 3.501 p-sig = 0.034. Since p value = sig .034 < 0.05, H_0 is rejected and H_1 is accepted.

The above table shows that the calculated F value is greater than the table value at 0.05 levels, the null hypothesis is rejected and concluded that “there is statistically significant

difference among the religion of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.4 Education and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the education of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the education of the respondents in the mean score of the parents of mentally retarded children.

Results: $F(3,106) = 0.929$ p. sig = 0.430. Since p value = sig 0.430 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated F value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the education of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.5 Occupation and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the occupation of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the occupation of the respondents in the mean score of the parents of mentally retarded children.

Results: $F(3,106) = 3,106$ p.sig = 0.430. Since p value = sig 0.430 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated F value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the occupation of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.6 Family Status and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the family of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the family of the respondents in the mean score of the parents of mentally retarded children.

Results: $T(108) = 1.063$ p.sig = 0.290. Since p value = sig 0.290 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated T value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the family status of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.7 Housing Status and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the housing status of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the housing status of the respondents in the mean score of the parents of mentally retarded children.

Results: $T(108) = 0.120$ p.sig = 0.905. Since p value = sig 0.905 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated T value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the housing status of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.8 Locality and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the locality of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the locality of the respondents in the mean score of the parents of mentally retarded children.

Results: T (108) – 1.463 p.sig = 0.146. Since p value = sig 0.146 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated T value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the locality of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.9 Monthly Income and Burden Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the monthly income of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the monthly income of the respondents in the mean score of the parents of mentally retarded children.

Results: F (2,107) – 1.479 p.sig = 0.232. Since p value = sig 0.023 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated F value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the Monthly Income of the respondents in the mean score of the Burden assessment of the mentally retarded children.

3.10 Saving Habit and Assessment of the Mentally Retarded Children

- H_0 – There is no statistically significant difference among the saving of the respondents in the mean score of the parents of mentally retarded children.
- H_1 – There is a statistically significant difference among the saving of the respondents in the mean score of the parents of mentally retarded children.

Results: T (108) – 1.157 p.sig = 0.250. Since p value = sig 0.0250 > 0.05, H_0 is accepted and H_1 is rejected.

The above table shows that the calculated T value is less than the table value at 0.05 levels, the null hypothesis is accepted and concluded that “there is no statistically significant difference among the saving habits of the respondents in the mean score of the Burden assessment of the mentally retarded children.

Table – 2: Associations of Social Economic Conditions and Self Esteem Cross Tabulation of Mentally Retarded Children

Category	Variables	Self Esteem		Total	Statistical Inference
		Low	High		
Age Group	Below 35 years	26	27	53	χ^2 - 3.650 Df - 2 Sig. 0.161 p>0.05
		49.1%	50.9%	100.0%	
	36-45 years	14	24	38	
		36.8%	63.2%	100.0%	
	Above 46 years	12	7	19	
		63.2%	36.8%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	
Gender	Male	29	31	60	χ^2 - 0.060 Df - 1 Sig. 0.807 P>0.05
		48.3%	51.7%	100.0%	
	Female	23	27	50	
		46.0%	54.0%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	
Religion	Hindu	38	44	82	χ^2 - 1.464 Df - 2 Sig. 0.481 p>0.05
		46.3%	53.7%	100.0%	
	Christian	7	10	17	
		41.2%	58.8%	100.0%	
	Muslim	7	4	11	
		63.6%	36.4%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	
Education	Illiterate	20	13	33	χ^2 - 4.052 Df - 3 Sig. 0.256 p>0.05
		60.6%	39.4%	100.0%	
	School	20	25	45	
		44.4%	55.6%	100.0%	
	Diploma	9	13	22	
		40.9%	59.1%	100.0%	
	Under Graduate	3	7	10	
		30.0%	70.0%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	
Occupation	Unemployed	19	17	36	χ^2 - 4.435 Df - 3 Sig. 0.218 p>0.05
		52.8%	47.2%	100.0%	
	Government	3	11	14	
		21.4%	78.6%	100.0%	
	Private	15	16	31	
		48.4%	51.6%	100.0%	
	Business	15	14	29	
		51.7%	48.3%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	

Family Status	Nuclear family	42	39	81	$\chi^2 - 2.585$ Df - 1 Sig. 0.108 p>0.05
		51.9%	48.1%	100.0%	
	Joint family	10	19	29	
		34.5%	65.5%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	
Housing Status	Own	30	28	58	$\chi^2 - 0.975$ Df - 1 Sig. 0.323 p>0.05
		51.7%	48.3%	100.0%	
	Rent	22	30	52	
		42.3%	57.7%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	
Locality	Rural	25	23	48	$\chi^2 - 0.791$ Df - 1 Sig. 0.374 p>0.05
		52.1%	47.9%	100.0%	
	Urban	27	35	62	
		43.5%	56.5%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	
Monthly Income	₹1,000 to ₹5,000	24	22	46	$\chi^2 - 1.496$ Df - 2 Sig. 0.473 p>0.05
		52.2%	47.8%	100.0%	
	₹5,001 to ₹10,000	20	22	42	
		47.6%	52.4%	100.0%	
	₹10,001 and above	8	14	22	
		36.4%	63.6%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	
Savings	Yes	13	21	34	$\chi^2 - 1.613$ Df - 1 Sig. 0.204 p>0.05
		38.2%	61.8%	100.0%	
	No	39	37	76	
		51.3%	48.7%	100.0%	
	Total	52	58	110	
		47.3%	52.7%	100.0%	

The above table indicates that there is no significant association between the age group, gender, religion, education, occupation, family status, housing status, locality, monthly income and self-respondents of their mentally retarded children. This shows that both of them educated and uneducated parents having a mentally retarded child have problems. Nearly, above one third of the respondents are illiterate and 45 per cent of the respondents are completed their school education. But there is no significant association between the education and the self-esteem.

Then, the 81 per cent of the respondents are from nuclear family and the remaining 29 per cent of the respondents are from traditional joint family system. But there is no significant association between the family status and self-esteem.

CONCLUSION

The Government of India, judicial system did little over the years to improve the existing laws and conditions of the mentally retarded, in terms of safeguarding their interests and instituting the need-based educational programmes and vocational training programmes to improve the overall quality of life of these individuals. Goel and Sen (1984) observed that “The Indian Lunacy Act of 1912 still governs the mental retardates. This Act does not make any difference between lunacy and mental retardation and this lacuna has been accepted by legal luminaries including judges”. With regard to the educational policy and planning by the Government, the authors observed that several conferences, meetings and seminars have been held, many commissions have been appointed, many recommendations have been made and ‘white papers’ have been issued... after Independence, compulsory education has been introduced though not implemented vigorously, it has brought a very large number of students under the educational system.

Article 41 of the Constitution of India (1950) embodied in its clause the “Right to Free and Compulsory Education for All Children up to Age 14 years”. Many more schools for persons with mental retardation were established including an integrated school in Mumbai. Notwithstanding this obligatory clause on children’s mainstream education, more and more special schools were also being set up by Non-Governmental Organizations (NGOs) in an attempt to meet the parents’ demands.

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